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College of Physicians & Surgeons of Columbia University | *New York, N.Y. 10032*

DEPARTMENT OF PSYCHIATRY

722 West 168th Street

June 27, 1991

ELSI Working Group

Dear Friends,

I am delighted to report to you that at the recent meeting of the joint NIH/DOE Program Advisory Committee for the Human Genome Project, our letter to the EEOC commenting on their proposed regulations for implementing the Americans with Disabilities Act was strongly and unanimously endorsed. The advisors questioned why the regulations were written in this fashion, to which, of course, we could provide no answer. The advisors emphasized their strong concern regarding the possible repercussions to individuals, families and society in general from the use of genetic information which would be flowing from the Human Genome Project. They stated that it would be remiss of them not to comment on potentially discriminatory practices and the abuse of genetic testing information.

A letter from the Chairs of the NIH/DOE Program Advisory Committee, Drs. Paul Berg and Sheldon Wolfe, will be sent to the EEOC. A request for endorsement will also be sent to the directors of these agencies for approval and endorsement at higher levels as well.

We were less successful in contacting members of the EEOC, who refused to meet with us. They are apparently prohibited by law from discussing details of rule making before the regulations are issued. However, we sent a letter to Senator Harkin's Disability Committee informing them of our concerns. We also plan to be in contact with representatives from the disabilities and genetic disorders community to alert them. Dr. David Cox, the liaison representative from the American Society for Human Genetics, will be taking our endorsement letter back to Dr. Thomas Caskey, President of that Society for possible action by their constituency. Any suggestions you have for additional people to contact, please send the names or feel free to contact them on your own.

The response to our Request for Applications (RFA) for pilot projects in cystic fibrosis (CF) testing was also uniformly well received. Since the last Program Advisory Committee meeting in December, 1990, in which the advisors instructed the National Center for Human Genome Research (NCHGR) to develop an RFA on CF testing, Dr. Elke Jordan, Deputy Director of the Center, and Dr. Eric Juengst, in charge of the ELSI program, went to Dr. William

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Raub, acting Director of the NIH, and convinced him of the necessity of this RFA. Although it is not typical for the NIH to sponsor clinical research protocols on the introduction of new tests, Dr. Raub was persuaded of the importance of this particular endeavor and strongly endorsed the RFA. These are not typical times.

A joint RFA with the National Center for Human Genome Research (NCGHR), National Institute for Digestive Disorders and Kidney (NIDDK - home institute of CF), and the National Center for Nursing Research was developed, distributed, and the applications received before the June Program Advisory Meeting. They will be reviewed and funded before the next meeting in January. This is a record achievement in speed by any standards. Dr. Eric Juengst, Dr. Elke Jordan, Dr. James Watson, Elinor Langfelder and the review branch of the Center are to be strongly congratulated for their alacrity in moving on this issue. We were all gratified to learn that there were 30 responses to the RFA. Review will take place in August for September council and the first of these projects will get under way in December, 1991. The advisors again made a strong plea to be informed of the concerns that the genetics community and the community at large have with respect to the dissemination of genetic information, and they emphasized their commitment to being highly attentive to the broad impact of the Genome Project as it unfolds.

On June 28, 1991, Michael Yesley and Phillip Reilly, of the Eunice Kennedy Shriver Center for Mental Retardation, Inc., organized a successful meeting which focused on issues of privacy. The meeting highlighted some of the key problems that the development of data bases and the impact of new technology will pose with respect to the preservation of privacy. The meeting was particularly useful as a planning session for the upcoming ELSI meeting in September. All the participants at this preliminary meeting will be joining us in September, as well as some additional invitees. (See the enclosed tentative outline for this meeting.)

The purpose of the meeting was also to discuss current legislation in the realm of privacy. The Conyers Bill was reintroduced into Congress but we have it on reliable authority that there is no intent to push this particular piece of legislation. The enforcement paragraphs were taken out because of conflict of committee jurisdiction and other problems with the legislation are now apparent to the Conyers committee. They may be interested in introducing revised legislation in the future, however.

The California Discrimination Bill was also discussed in Friday's meeting. It would appear that this bill does not add any additional protections to the Unruh civil rights legislation currently in the California Code. The act makes explicit that

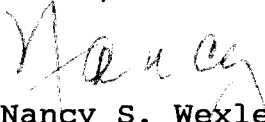
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genetic discrimination is forbidden and, as such, may be useful to have in law. On the other hand, if the legislators pass this bill believing that they are providing real or new protections, they are misinformed. We do not want them to expend energy on creating legislation that is marginally useful if we need to recruit their cooperation in the future to pass legislation with more teeth.

We will certainly discuss these pieces of legislation further in the September meeting.

I look forward to seeing you again in September - although the prospect of summer having come and gone by that time is dismaying. I hope you are able to enjoy a little bliss and unencumbered time this summer. ELSI is coming of age and we're DOING OKAY! Many Thanks.

Yours,


Nancy S. Wexler, Ph.D.
Associate Professor
Clinical Neuropsychology

P.S. I am including some recent articles which I hope you may find of interest (I did not title my section of the LA Times Magazine article, "Life in the Lab." I think the Times became enchanted with the alliteration, but that's the way of all editing.)

ELSI - September, 1991
Draft Program

I. What is privacy and why do we value it? Anita Allen

II. Scope of privacy:

- A. Do groups have privacy?
- B. Violation of privacy by anonymous disclosure.
- C. Rationales for breach of privacy.

III. Data Banks

- A. What exists: from the FBI to the file in the bottom drawer - what's out there? Phil Reilly
- B. Computers and privacy.
- C. Technology today and tomorrow: how do banks protect now and what do the futurologists have to say in this arena?

IV. How do we protect privacy?

- A. International perspective. Bartha Koeppels
- B. The current practices. Lori Andrews
- C. Federal and State Legislation: Is Federal legislation the best avenue or State by State protections? Should laws be aimed at genetic privacy or should genetics be integrated into legislation and policy aimed at medical privacy in general?
Harold Edgar

V. What should ELSI do?

There will be a general directive to all speakers in each section to consider this question. The summary discussion will focus on ways in which we as the Working Group can advance research and activities in this most critical area.

This is a tentative outline. Speakers for some sections have been suggested but have not yet been contacted. If you have any thoughts or suggestions regarding this outline, please let Michael or myself know. Also, we can invite some participants who may not be speakers but whose input would be valuable for our discussion.